

AMENDED IN SENATE MAY 23, 2008

AMENDED IN SENATE APRIL 17, 2008

AMENDED IN SENATE APRIL 3, 2008

SENATE BILL

No. 1502

Introduced by Senator Steinberg

(Principal coauthor: Assembly Member Garrick)

*(Coauthors: Assembly Members Adams, Aghazarian, Cook, Silva, Smyth,
and Strickland)*

February 21, 2008

~~An act to add Chapter 9 (commencing with Section 104324.6) to Part 1 of Division 103 of the Health and Safety Code, and to add and repeal~~
An act to add and repeal Article 17 (commencing with Section 18881)
of Chapter 3 of Part 10.2 of Division 2 of the Revenue and Taxation Code, relating to amyotrophic lateral sclerosis (ALS).

LEGISLATIVE COUNSEL'S DIGEST

SB 1502, as amended, Steinberg. Amyotrophic lateral sclerosis (ALS).

~~(1) Existing law makes various provisions for the prevention of disease, including chronic diseases, and the promotion of health, and requires the State Department of Public Health to implement and administer various health promotion and preventative health services.~~

~~This bill would declare the intent of the Legislature that it is in the interest of the state to better serve the thousands of persons with amyotrophic lateral sclerosis (ALS) and their families who are currently struggling with ALS or to care for a family member with ALS, that research for ALS remains the only real hope for an effective treatment and cure for persons with ALS and their families, and that this state~~

~~should take the lead for a robust program of innovative and creative research for an effective treatment and, ultimately, a cure for ALS.~~

~~(2) Provisions~~

~~Existing law contains various provisions relating to the administration of personal income taxes—allow~~ *allowing* individual taxpayers to contribute amounts in excess of their tax liability for the support of specified funds.

This bill would ~~additionally~~ allow taxpayers to designate on their tax returns that a specified amount in excess of their tax liability be transferred to the ALS/Lou Gehrig's Disease Research Fund, which would be created by this bill.

This bill would provide that all money contributed to the fund pursuant to these provisions would be subject to appropriation by the Legislature, as specified.

This bill would provide that these voluntary contribution provisions are repealed on January 1, 2013; or for the taxable year beginning on or after January 1 of the calendar year in which the Franchise Tax Board estimates, by September 1, that the contributions made on returns filed in that calendar year will be less than a minimum contribution amount, whichever occurs first.

Vote: majority. Appropriation: no. Fiscal committee: yes.
State-mandated local program: no.

The people of the State of California do enact as follows:

1 ~~SECTION 1. Chapter 9 (commencing with Section 104324.6)~~
2 ~~is added to Part 1 of Division 103 of the Health and Safety Code,~~
3 ~~to read:~~

4
5 ~~CHAPTER 9. STATEWIDE ALS DISEASE AND RELATED DISORDERS~~
6 ~~RESEARCH POLICY~~

7
8 ~~104324.6. The Legislature finds and declares all of the~~
9 ~~following:~~

10 ~~(a) Amyotrophic lateral sclerosis (ALS), often referred to as~~
11 ~~Lou Gehrig's Disease, is a progressive neurodegenerative disease~~
12 ~~that affects motor neurons in the brain and the spinal cord. On~~
13 ~~average, persons with ALS (PALS) die within two to five years~~
14 ~~of diagnosis.~~

1 ~~(b) In the 150 years since ALS was identified as a disease, there~~
2 ~~is still no known cause, prevention, treatment, or cure.~~

3 ~~(c) It is estimated that there are more than 30,000 Americans,~~
4 ~~including several thousand Californians, who have ALS and related~~
5 ~~disorders at any given time. Based on United States' population~~
6 ~~studies, a little more than 5,600 people in the United States are~~
7 ~~diagnosed with ALS each year. Approximately every 90 minutes,~~
8 ~~someone is diagnosed with ALS, and every 90 minutes someone~~
9 ~~else dies from ALS.~~

10 ~~(d) Veterans are 60 percent more likely, and Gulf and Iraqi War~~
11 ~~Veterans twice as likely, to get ALS than the general population.~~

12 ~~(e) Research has shown that coordinated and comprehensive~~
13 ~~community-based clinical care provided within a multidisciplinary~~
14 ~~treatment program can marginally extend life and improve the~~
15 ~~quality of life for PALS.~~

16 ~~(f) ALS affects the PALS' family as the burden of care falls~~
17 ~~largely on them. In the later stages of the disease, this amounts to~~
18 ~~24-hour, seven-day-a-week regimen and the need for respite care~~
19 ~~for these caregivers. The costs of the disease escalates well into~~
20 ~~the six figures during this stressful and emotional period, often~~
21 ~~after a spouse, child, or other family member quits working to care~~
22 ~~for their loved one, thereby depleting family savings and resources.~~

23 ~~(g) The incidence of ALS and related disorders in California~~
24 ~~will increase as the state's population of baby boomers ages.~~

25 ~~(h) The surge in the numbers of those persons affected by ALS,~~
26 ~~including family caregivers, will place a severe strain on the state's~~
27 ~~already challenged health, social services, geriatric, and other~~
28 ~~service delivery systems.~~

29 ~~(i) Advances in ALS disease research and promising ongoing~~
30 ~~clinical trials are testing agents that may slow progress of the~~
31 ~~disease, delay its onset, and some day prevent the disease~~
32 ~~altogether, as well as more effectively manage challenging~~
33 ~~symptoms.~~

34 ~~(j) Genetics, toxic agents, and stress are all suspected as possible~~
35 ~~causes of the disease. However, further research is needed to~~
36 ~~determine whether any or all of these, or possibly other, factors~~
37 ~~are the cause or causes of ALS and related disorders.~~

38 ~~(k) ALS Centers of Excellence, clinics, and centers and other~~
39 ~~entities have made significant contributions to the advancement~~
40 ~~of ALS disease research, and it is imperative for the state to have~~

~~primary care and long-term care delivery systems that are positioned to utilize these research findings to improve care for PALS living with ALS and related disorders.~~

~~(l) While advances in ALS research create hope for the future, they will not head off the increasing need for community, home, and residential in-home and respite care that is equipped to care for PALS suffering from ALS and related disorders. In-home and respite care are nonexistent or woefully inadequate for PALS and their families.~~

~~(m) To help avoid bankrupting our health and social service systems serving Californians, California must prepare now by identifying strategies that will provide appropriate care to families coping with and caring for a family member afflicted with ALS.~~

~~(n) It is in the interest of the state to better serve the thousands of PALS and their families statewide who are currently struggling with ALS or to care for a family member with ALS.~~

~~(o) Research for ALS remains the only real hope for an effective treatment and cure for PALS and their families.~~

~~104324.61. (a) The System of Care for ALS in California, described in companion Senate Bill 1503 of the 2007–08 Regular Session, including existing and future Centers of Excellence, and other entities have improved the quality of care available to the victims of ALS and increased knowledge with respect to ALS and related disorders. ALS is an insidious killer of thousands of Californians. It absorbs millions of dollars from California's economy through health care costs, and takes a tremendous toll on the personal lives of its citizens.~~

~~(b) In recognition of the fact that there is no known cause, prevention, treatment, or cure for ALS, and that research for ALS is the only real hope for an effective treatment and cure for PALS and their families, it is the policy of this state that California should take the lead for a robust program of innovative and creative research for an effective treatment and, ultimately, a cure for ALS.~~

~~(c) The Centers of Excellence described in companion Senate Bill 1503 of the 2007–08 Regular Session and other entities provide clinical opportunities for research and facilitate the collection of essential data regarding ALS, while at the same time providing valuable services, such as information and referral, counseling, and training to ALS victims and their families. ALS Centers of Excellence, postsecondary higher educational institutions, medical~~

1 centers, hospitals, other medical facilities, research facilities, health
2 care organizations, and private industry all should participate in
3 research to discover the cause of, and ultimately a cure for, ALS.

4 (d) ~~ALS research should encompass the cause, prevention, cure,~~
5 ~~diagnosis, and treatment of ALS, including, without limitation,~~
6 ~~research in the fields of neurology, biomedical science and~~
7 ~~engineering, economics, epidemiology, diet and lifestyle, public~~
8 ~~health and technology development, and translation. In addition,~~
9 ~~this program should provide for the systematic dissemination of~~
10 ~~research results to the public and the health care community, and~~
11 ~~provide for a mechanism to disseminate the most current research~~
12 ~~findings in the areas of cause, treatment, cure, earlier detection,~~
13 ~~and prevention of ALS, in order that these findings may be applied~~
14 ~~to the planning, implementation, and evaluation of this program.~~

15 (e) ~~The functions of the Centers of Excellence and other research~~
16 ~~entities described above should include all of the following:~~

17 (1) ~~To increase research in discovering the cause of, and a cure~~
18 ~~for, ALS.~~

19 (2) ~~To increase the training of health care professionals and~~
20 ~~researchers with respect to ALS and other acquired brain~~
21 ~~impairments to the extent that they have the requisite expertise.~~

22 ~~SEC. 2.~~

23 *SECTION 1.* Article 17 (commencing with Section 18881) is
24 added to Chapter 3 of Part 10.2 of Division 2 of the Revenue and
25 Taxation Code, to read:

26
27 Article 17. ALS/Lou Gehrig's Disease Research Fund
28

29 18881. The Legislature finds and declares all of the following:

30 (a) ~~Amyotrophic Lateral Sclerosis~~ *lateral sclerosis* (ALS), more
31 commonly known as Lou Gehrig's disease, is a degenerative
32 disease of the motor nerves that causes progressive weakness of
33 all voluntary muscles. People with ALS become unable to move,
34 swallow, speak, and breathe without assistance, usually remaining
35 fully aware of what is happening to them and their families.

36 (b) ALS is a fatal disease. There is no cure and only one drug
37 therapy, which allows the patient a month or two more of life.
38 Most ALS patients die within two to five years of symptom onset.
39 Every 90 minutes someone is diagnosed with ALS and every 90
40 minutes someone dies of the disease. ALS knows no racial, ethnic,

1 or socioeconomic boundaries, often striking people at midlife and
2 at the height of family and financial responsibilities.

3 (c) The devastating physical, emotional, and financial effects
4 caused by the progression of ALS and the 24-hour,
5 seven-day-a-week caregiving required impacts not only the patient,
6 but the entire family. ALS is a family disease and the need for
7 research is dire.

8 (d) It is the intent of the Legislature, in enacting this article, to
9 establish a systematic program to conduct research regarding the
10 cause, cure, and prevention of ALS. The outcome of this research
11 may have direct effects and consequences on the development of
12 a comprehensive system that may identify the cause, cure, and
13 prevention of ALS, as well as improving the screening, diagnosis,
14 and treatment of victims of ALS. This program shall award grants
15 to eligible physicians, hospitals, laboratories, educational
16 institutions, and other organizations and persons for the purpose
17 of enabling organizations and persons to conduct research.

18 18882. (a) Any individual may designate on the tax return that
19 a contribution in excess of the tax liability, if any, be made to the
20 ALS/Lou Gehrig's Disease Research Fund, which is established
21 by Section 18883.

22 (b) The contribution shall be in full dollar amounts and may be
23 made individually by each signatory on a joint return.

24 (c) A designation under subdivision (a) shall be made for any
25 taxable year on the individual return for that taxable year, and once
26 made shall be irrevocable. In the event that payment and credits
27 reported on the return, together with any other credits associated
28 with the individual's account, do not exceed the individual's
29 liability, the return shall be treated as though no designation has
30 been made.

31 (d) The Franchise Tax Board shall revise the forms of the return
32 to include a space labeled the "ALS/Lou Gehrig's Disease Research
33 Fund" to allow for the designation permitted under subdivision
34 (a). The forms shall also include in the instructions, information
35 that the contribution may be in the amount of one dollar (\$1) or
36 more and that the contribution shall be used to conduct research
37 relating to the cure, screening, and treatment of ALS.

38 (e) It is the intent of the Legislature that the 2008 tax return
39 include a space for the ALS/Lou Gehrig's Disease Research Fund.

1 (f) A deduction shall be allowed under Article 6 (commencing
2 with Section 17201) of Chapter 3 of Part 10 for any contribution
3 made pursuant to subdivision (a).

4 18883. There is hereby established in the State Treasury the
5 ALS/Lou Gehrig's Disease Research Fund to receive contributions
6 made pursuant to Section 18882. The Franchise Tax Board shall
7 notify the Controller of both the amount of money paid by
8 taxpayers in excess of their tax liability and the amount of refund
9 money which taxpayers have designated pursuant to Section 18882
10 to be transferred to the ALS/Lou Gehrig's Disease Research Fund.
11 The Controller shall transfer from the Personal Income Tax Fund
12 to the ALS/Lou Gehrig's Disease Research Fund an amount not
13 in excess of the sum of the amounts designated by individuals
14 pursuant to Section 18882 for payment into that fund.

15 18884. All money transferred to the ALS/Lou Gehrig's Disease
16 Research Fund, upon appropriation by the Legislature, shall be
17 allocated as follows:

18 (a) To the Franchise Tax Board and the Controller for
19 reimbursement of all costs incurred by the Franchise Tax Board
20 and the Controller in connection with their duties under this article.

21 (b) To the State Department of Public Health, to provide grants
22 for the conduct of research to physicians, hospitals, laboratories,
23 educational institutions, and other organizations and persons, *and*
24 *to reimburse any costs incurred by the department for*
25 *administering the grant program pursuant to this section.*

26 18885. For the purpose of this article, "research" shall include,
27 but not be limited to, expenditures to develop and advance the
28 understanding, techniques, and modalities effective in the
29 prevention, cure, screening and treatment of ALS.

30 18886. (a) Unless repealed earlier pursuant to subdivision (b),
31 this article shall remain in effect only until January 1, 2013, and
32 as of that date is repealed, unless a later enacted statute, which is
33 enacted before January 1, 2013, deletes or extends that date.

34 ~~(b) (1) By September 1, 2009, and by September 1 of each~~
35 ~~subsequent calendar year that the ALS/Lou Gehrig's Disease~~
36 ~~Research Fund appears on a tax return, the Franchise Tax Board~~
37 ~~shall determine whether the amount of contributions estimated to~~
38 ~~be received during the calendar year will equal or exceed the~~
39 ~~minimum contribution amount. The Franchise Tax Board shall~~
40 ~~estimate the amount of contributions to be received by using the~~

1 ~~actual amounts received and an estimate of the contributions that~~
2 ~~will be received by the end of that calendar year.~~

3 (b) (1) By September 1, 2009, and by September 1 of each
4 subsequent calendar year that the ALS/Lou Gehrig's Disease
5 Research Fund appears on the tax return, the Franchise Tax Board
6 shall do all of the following:

7 (A) Determine the minimum contribution amount required to
8 be received during the next calendar year for the fund to appear
9 on the tax return for the taxable year that includes the next
10 calendar year.

11 (B) Provide written notification to the State Department of
12 Public Health of the amount determined in subparagraph (A).

13 (C) Determine whether the amount of contributions estimated
14 to be received during the calendar year will equal or exceed the
15 minimum contribution amount determined by the Franchise Tax
16 Board for the calendar year pursuant to subparagraph (A). The
17 Franchise Tax Board shall estimate the amount of contributions
18 to be received by using the actual amounts received and an
19 estimate of the contributions that will be received by the end of
20 that calendar year.

21 (2) If the Franchise Tax Board determines that the amount of
22 contributions estimated to be received during a calendar year will
23 not at least equal the minimum contribution amount for the calendar
24 year, this article is repealed with respect to taxable years beginning
25 on or after January 1 of that calendar year.

26 (3) For purposes of this section, "minimum contribution amount"
27 for a calendar year means two hundred fifty thousand dollars
28 (\$250,000) for calendar year 2010, or the minimum contribution
29 amount adjusted pursuant to subdivision (c).

30 (c) For each calendar year beginning with the 2011 calendar
31 year, the Franchise Tax Board shall adjust, on or before September
32 1 of that calendar year, the minimum contribution amount specified
33 in subdivision (b) as follows:

34 (1) The minimum contribution amount for the calendar year
35 shall be an amount equal to the product of the minimum
36 contribution amount for the prior calendar year multiplied by the
37 inflation factor adjustment as specified in paragraph (2) of
38 subdivision (h) of Section 17041, rounded off to the nearest dollar.

39 (2) The inflation factor adjustment used for the calendar year
40 shall be based on the figures for the percentage change in the

1 California Consumer Price Index received on or before August 1
2 of the calendar year pursuant to paragraph (1) of subdivision (h)
3 of Section 17041.

4 (d) Notwithstanding the repeal of this article, any contribution
5 amounts designated pursuant to this article prior to its repeal shall
6 continue to be transferred and disbursed in accordance with this
7 article as in effect immediately prior to that repeal.

O